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# Thyroid Autoimmunity: Lived Experiences of Identity and Community through Word and Image

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Thyroid Autoimmunity:  
Lived Experiences of Identity and Community through Word and Image

Submitted by Ivy C. Wagner  
May 2012

MSW Clinical Research Paper

The Clinical Research Paper is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publically present their findings. This project is neither a Master's thesis nor a dissertation.

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### **Abstract**

Internal and external environments influence holistic well-being as humans live in a constant cycle of self and other regulation. When this process is misguided and the body does not distinguish between what is self and what is not self, it begins to destroy its own bodies' healthy tissue. Autoimmune diseases affect 5-10% of the developed world's populations. When the 80+ autoimmune diseases are combined together, they are the one of the 10 leading causes of death of women under the age of 65. There is no known cure for any autoimmune disease and few studies have been conducted on the emotional and spiritual energetic underpinnings of autoimmune disease. The purpose of this research was to explore the connections between identity, community and thyroid autoimmunity, adding to the emerging and growing understanding of the current epidemic of autoimmunity. The original creation of an arts-based, phenomenological research methodology was presented. Eight participants provided their lived experience in photographs using modified PhotoVoice methods and written reflections through open ended questions in project notebooks. Data was analyzed and represented through narrative methods. Findings support further exploration of mental autoimmunity, the inability to emotionally and spiritually recognize and voice the story of self, and its role in a person's susceptibility to physical autoimmune illness. Implications for clinical practice and future research recommendations were discussed.

*Keywords:* autoimmune disease, autoimmunity, story, identity, PhotoVoice, thyroid, narrative theory

## Acknowledgments

Together, I honor my own collection of stories. My first peak into a treasure chest in the basement of my grandparents' church. The BFG Dream Jar. Dr. Clouser's Star. Evenings of peace with Joe. Matthew's waterfall. Evan and the Bears. Tuesday mornings with Dr. Dailey. Silence with Brother Richard. A fortunate 24 hours with Jonah and Sarah in Asheville. The nine witnesses in Evanston who were held and rooted at Reba's Place. The countless pictures, pieces and words captured in my journal pages, collected from every person and community I met on my global wanderings, have finally integrated. For each nurse and endocrinologist who cared for me. I am grateful to each. I would not be Ivy without 'two both'. I slept. I crept. Now I leap.

I acknowledge those who have walked with me on this nine-month journey. Kari's patience and trust in the moments she experienced little visible movement and growth within me. The ideas and wisdom that emerged from two gatherings with Carol, Barbara, Jodi and Mary Beth. Phone calls with Carolyn, Chad, Don and Dustin at the 11<sup>th</sup> hour. Being with Zeek as he was dying of a canine autoimmune disease. The eight participants who showed up and finished. I hold their stories and pictures as sacred.

On this, my 30<sup>th</sup> year of life, and the 14<sup>th</sup> year of being cancer free, I dedicate this research to all those who long to be seen and heard. To each one who desires a connection to another. To all those who have not been protected from radioactive fallout. To the thyroid and our body's mysterious relationship with mind, heart and soul.

We are not sick and dying. We are alive and well.

This is the story of me coming home.

Asante sana. Ngiyabonga. Thank you.



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## Introduction

Listening to and speaking story are two of the most powerful pieces of collective human experience. Stories are everywhere. The stories told and those left untold. There are secret stories, family stories, political stories, cultural stories, religious stories and stories that say there are no stories. People use stories to shape how they see and experience themselves in their world. Likewise, the story of self and how self is embodied is formed by connection to family, community and culture. Storying is the way humans receive, define, process, assimilate and express life experience.

In a similar way, the human body writes its story through energy and chemical signals. A constant process of metabolism, obtaining, releasing and utilizing energy, enables the maintenance of *homeostasis*, a stable internal environment (Shier, Butler & Lewis, 2007). In order to remain in a state of homeostasis, humans enter into the tension between self and other (non-self) regulation. A cyclical sequence of self and other regulation, dysregulation and reregulation generates confidence that disruptions can be safely repaired for the maintenance of homeostasis.

Maintenance of homeostasis requires the immune system's white blood cells to protect the body from antigens. *Antigens* are bacteria, viruses, fungi, chemicals, parasites, toxins, cancer cells, blood and tissues from another person or species (Post-White, 1996). Nonspecific (innate) immunity includes general defense mechanisms present at birth, such as skin, pH, enzymes and immune cells. Over a lifetime, specific (acquired or adaptive) immunity is created by antibodies (proteins) through a recognition system based on previous encounters with antigens. Identified substances are cataloged as threat or not threat in an extensive bodily library. If this process is misguided, the

immune system may begin destroying its own bodies' healthy tissue. As the immune system's ability to distinguish self from non self is compromised, it begins to create *autoantibodies* which destroy its own body's healthy cells, organs or tissues. This malfunction is clinically diagnosed as an *autoimmune disease*.

Since Ehrlich (1906) first postulated the existence of self-directed antibodies to specific organs, a condition he called *horror autotoxicus*, over 80 different autoimmune diseases have been identified and 40 additional diseases are suspected to have an autoimmune basis (AARDA, 2010). The misguided autoimmune response can be localized to a single organ, a single tissue or may target many different organs and tissues (see Figure 1). Several reports indicate autoimmune diseases collectively affect approximately 5-10% of the developed world's population (Eaton, 2006). Between 15.5 and 50 million Americans (up to 1 in 5) are living with an autoimmune disease (National Institute of Health, 2005). In comparison, cancer affects up to 9 million and heart disease up to 22 million people (AARDA, 2010).

The relative female to male prevalence ratio varies significantly across the spectrum of specific autoimmune diseases. Jacobsen (1997) reported data showing females, on average, were 2.6 times more likely than males to develop 24 of the autoimmune diseases evaluated. Females comprised 75% of the cases of autoimmunity (National Women's Health Information Center, 2010). When viewed together, autoimmune diseases constitute one of the 10 leading causes of death among American women younger than 65 years (Walsh & Rau, 2000).

The specific mechanisms which cause autoimmune disease remain unknown. Genetic susceptibility may account for about half of the risk for developing an

autoimmune disease (Baron-Faust, 2003). Autoimmune diseases may be triggered by an infectious agent, like a virus or bacteria. Environmental exposure, such as prescription drugs, hormones, pro-inflammatory diets, endocrine disruptors, sunlight, industrial chemicals, food additives and heavy metals may play a role in vulnerability to the disease (Tobias, 2010). These environmental factors are particularly important in individuals who have inherited a heightened genetic susceptibility.

Without a definite causation mechanism, the development of treatment has been slow. There is currently no cure for any of the autoimmune diseases. Current understanding of autoimmune disease supports palliative treatment models, immunosuppressant drugs, symptom management and support groups as treatment options (AARDA, 2010). The unpredictable, cyclical nature of symptoms, with surges of activity and periods of remission, leads to life-long treatment. The annual direct cost of all autoimmune disease has been estimated by the National Institute of Health to be in the range of \$100 billion (Tobias, 2010). Reports from MarketsandMarkets and the Global Industry Analysts, Inc, forecast the total global autoimmune drug-treatment market (i.e., biologics and small molecules) will reach \$49.8 to \$68.8 billion by 2014-15 (AARDA, 2010). The vast majority of available therapies and drug development programs represent no more than ten of the currently identified total of 151 autoimmune or autoimmune-related diseases (Tobias, 2010).

Since its inception in the early 1940s, psychosomatic medicine has provided the scientific foundation for the bio-psycho-social model (Novack et al, 2007). Psychoneuroimmunology (PNI) is opening understanding of the ways the mind, nervous system and immunity are related. Very little is known about the bio-psycho-social-

spiritual dynamics which may create vulnerability and susceptibility to autoimmune disease.

This paper discusses current theoretical understanding and literature about self, illness and stress. The design and creation of an arts-based, phenomenological research methodology is presented. Findings from written stories and images are analyzed through a narrative approach. Discussion of *mental autoimmunity*, the inability to emotionally and spiritually recognize and voice the story of self, and its role in a person's susceptibility to thyroid autoimmunity is explored. The purpose of this research study is to explore the connections between identity, community and thyroid autoimmunity, adding to the emerging and growing understanding of the current epidemic of autoimmunity.

Rheumatoid arthritis (RA) and Juvenile RA (JRA)	• Joints
Systemic lupus erythematosus	• Skin, joints, kidneys, heart, brain, and red blood cells
Guillain-Barre syndrome	• Nervous system
Type 1 Diabetes Mellitus	• Pancreas
Hashimoto's thyroiditis and Graves' disease	• Thyroid gland
Celiac disease, Crohn's disease, Ulcerative colitis and Inflammatory Bowel Disease	• Gastrointestinal tract
Multiple sclerosis	• Central nervous system
Addison's disease	• Adrenal glands
Autoimmune hepatitis	• Liver
Vitiligo	• Skin pigment

*Figure 1.* Common Autoimmune Diseases and the Organs Targeted by Autoantibodies.

Created from data available on American Autoimmune Related Diseases Association.

(2010, October). *AARDA Facts*. Retrieved from [http://www.aarda.org/aarda\\_facts.php](http://www.aarda.org/aarda_facts.php)



## **Conceptual Framework**

In research, a conceptual framework provides a context for the key ideas and variables in a study. It is a lens through which presumed relationships can be understood. The purpose of a research conceptual framework is to bring greater clarity to the assumptive world underpinning the formulation of the research question. It becomes a guide, supporting and explaining the concepts and design of the research. Narrative theory, systems theory and the ecological perspective were fundamental theoretical lenses informing the development of this research study exploring the intersection of autoimmunity, identity and community.

Human beings are in relationship with their environment as they seek to meet their physical, emotional and spiritual needs and obtain support for healthy self-development. When a goodness of fit is not available, the interactions between self and other become dysfunctional. Early stress or trauma may not allow a parent and child to become attuned to each other's inner states through mutual exchange and internal adaptation. The permeable boundary between group and individual identity, personal and communal roles may become rigid or non-existent. Humans may begin to question their identity and how they fit into the social community. They are not recognized and welcomed for who they are. Disconnection and disease may emerge as energy flow and communication are disrupted.

## **Narrative Theory**

*Narrative theory* is concerned with the stories of person's lives, the experiences residing in these stories, and the context in which these stories are experienced (Connelly & Clandinin, 1990). Narrative theory supports an approach to therapy and community

work that centers people as experts in their own lives and views problems as separate from people (Dulwich Center, 2007). The word narrative refers to the emphasis placed upon the stories of people's lives and the differences that can be made through particular telling and retellings of the stories. Stories are made up of events, linked by a theme, occurring over time and according to plot (White & Epston, 1990). A thin story, when connected to other stories, becomes a thicker, congruent story. In the connections, multiple stories are developed that were not predicted by the dominant problematic story of people's lives. Identity changes over time and is relational, storied and membered (Freedman, 2012). Aspects of identity develop through relationship and are unpacked through stories. Narrative medicine and illness narratives are powerful forms of healing that have entered health care systems and medical establishments in recent times. This movement is reflective of ancient shaman archetype of healing. Narrative therapy's tool of externalizing the problem transforms the concept of disease. The problem of the illness is in relation to the person and the person is not an autoimmune disease. Narrative theory informed the development and discussion of this research study, providing the framework for honoring the stories of the participants.

### **Systems Theory**

All social systems are holons, meaning each system is part of a larger system, while at the same time composed of smaller systems (Miley, O'Melia & DuBois, 2011). All systems have subsystems and environments. Boundaries define systems, distinguishing the interior of the system from its environment. Boundaries vary in permeability, dictating the number of allowable transactions between systems, while differentiating what or who is in a given system. A system tends to interact in ways that

maintain its balance or equilibrium. When imbalance occurs, a system regains its previous equilibrium or establishes a new one. Feedback provides a continuous flow of information into the system. If the information fits into the system's existing structures, it is assimilated, reinforcing current patterns. Incompatible information forces change in the system to accommodate the discrepancy. Definition and boundary is important to the human body and its ability to protect and defend against disease. Systems theory brought clarity to the multiple layers of interactions between self and other that play a role in one's quality of well-being and health.

### **Ecological Perspective**

Concepts from ecology describe the constant relational transactions which occur between systems and their environments. The social work ecological perspective places every person in an environment and explores how the person interacts with the life-sustaining resources in his or her ecosystems (Forte, 2007). Bronfenbrenner (1979) created a four level framework to illustrate how individual or groups are influenced by the environmental systems in which they function (see Figure 2). Microsystem is the most basic system, referring to an individual's most immediate environment. Mesosystem refers to the interactional processes between multiple microsystems. Exosystems are settings which indirectly affect interactions on the micro and meso levels. Macrosystem are political, cultural, economic and social forces affecting individuals and group functioning.

**Goodness of fit.** The human being is in complex, continuous interaction with all four types of systems, micro through macro. A person's functioning on physical, biochemical, emotional, psychosocial and spiritual levels is affected by his or his ability

to participate in a symbiotic relationship of giving and receiving within internal and external environments (see Figure 3). As humans, environments and systems interact, a goodness of fit will emerge between an individual and the places in which life is lived. As humans seek to meet their needs and desires, systems and environments will change and stabilize in response to the feedback. How well the environment meets the needs of a person determines the level of goodness of fit.

Interactions with the environment people find themselves in begin to shape and reshape their identities. If there is a goodness of fit between person and environment, the foundation for a healthy self-concept and stable self-esteem is laid down (Thomas & Chess, 1977). If there is a poorness of fit, a negative, denigrated self-evaluation begins to crystallize. If, in latter childhood or even in adult life, a poorness of fit can be altered, such as by the emergence of new positive capacities or a favorable change in the environment, then a negative self-image may be transformed into a positive one. In this study, person-in-environment and goodness of fit were concepts that fostered exploration of the intersection between self and other. Understanding how the participants saw themselves in relation to their environments was a central concern in the development of the research instruments.

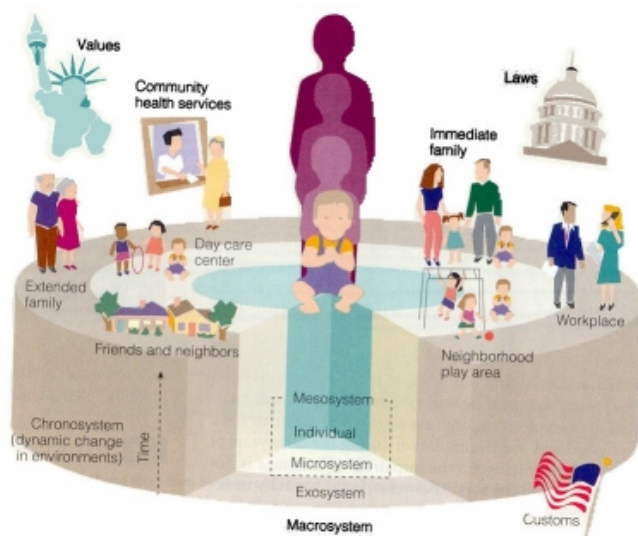


Figure 2. Bronfenbrenner's Ecological Systems Theory. Bronfenbrenners Ecological Systems Theory. (2012). *Bronfenbrenners Ecological Systems Theory*. Retrieved from <http://edfd127.wikispaces.com/Bronfenbrenners+Ecological+Systems+Theory>

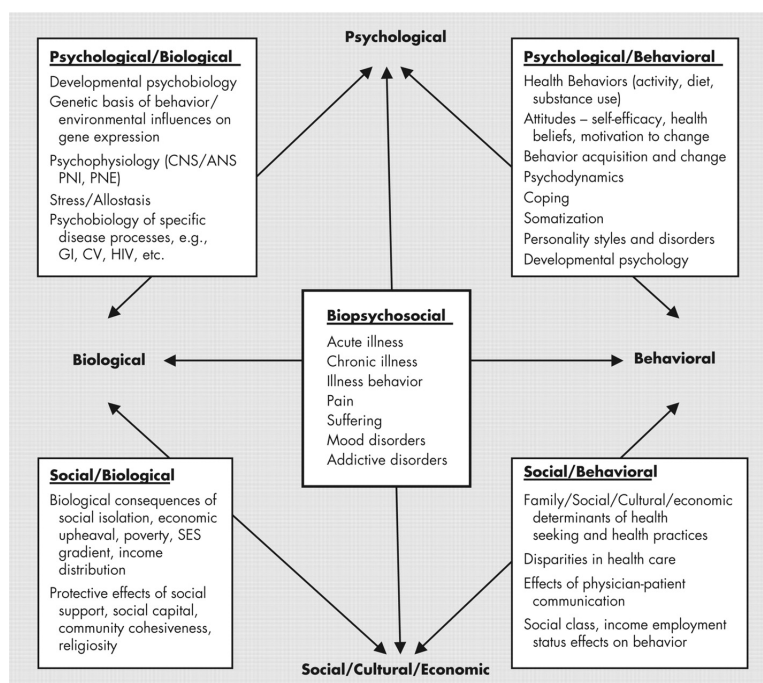


Figure 3. The Domains of Interaction in the Biopsychosocial Environment. Novack, D.H., Cameron, O., Epel, E., Ader, R., Waldstein, S.R., Levenstein, S., Antoni, M.H., & Wainer, A.R. (2007). Psychosomatic medicine: The scientific foundation of the biopsychosocial model. *Academic Psychiatry*, 31, 388–401.

## Professional Clinical Social Work Lens

The primary mission of the social work profession is to enhance well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable and oppressed (NASW Code of Ethics, 1999). In honoring professional values, social workers focus on the social and psychological factors associated with chronic illness. Autoimmune diseases are invisible conditions which create a spiral of complicating costs for clients: loss of job, loss of organ function, disability, debilitating symptoms, multiple diagnoses, hospitalization, emotional stress and relational difficulties. Social Security Disability considers many autoimmune conditions and endocrine disorders to be disabling (Disability Evaluation Under Social Security, 2011). The American Autoimmune Related Diseases Association, a leading voice in raising awareness about the growing epidemic, houses an online support group blog on their website. In a posting from the American Autoimmune Related Diseases Association Autoimmunity Forum (2010), a woman highlights the significant complications that co-exist with an autoimmune disease diagnosis.

*I have ankylosing spondylitis, inflammatory bowel disease, asthma, hypothyroidism, recurring MRSA, peripheral neuropathy, unrelenting nerve pain. I have had 6 surgeries in the last 8 months. I live in Wisconsin and am able to live in HUD housing due to my disability. It's a crappy place to live but it is a roof over my head. Because of mental health issues, I have lost the ability to control my health. Some days I feel like my body is attacking one thing after another. I currently take 19 prescriptions, 36 pills, plus shots, inhalers, pain patches, powders, and am in the middle of a trial for a second spinal cord stimulator*

*implant. The first was put in my lower back. This one is for the pain that starts at my occipital nerve and travels to the middle of my shoulder blades. To do this trial, I had to have all the hair shaved off of the back of my head to have wires inserted into my spine and skull. Just when I thought there could be no further indignity that my illness could force on me, now I have a shorter haircut than my son in the Marines. I do receive SSDI, but until I was approved, we were living off my high school senior's part time job. Can't feel any lower as a parent than to have to ask a child to be the sole breadwinner.*

Social workers have positioned themselves theoretically and practically to be of great assistance to those who are living with autoimmune diseases and those in supportive, caretaking roles. Autoimmune disease tends to run in families, with multiple family members affected by the same condition or multiple autoimmune diseases occurring in the same family. The family system must change to accommodate new lifestyles, diet and limitations of energy and work. Understanding how systems and environments affect individuals informs the cyclical process of disease, from onset to diagnosis through treatment. Clinical therapy focused on strengths and capacities for healing supports patients as they acknowledge the ways co-existing physical and mental illnesses have shaped their lives. Seeing autoimmune disease through the lens of micro, meso and macro levels, influenced by synergy of polity, social structures, economy and religion, opens up possibilities in research, policy and individual healing. Social workers have a responsibility to advocate for deeper understanding of the interplay between the physical and emotional realities, asking for equal attention to be dedicated to autoimmunity because it does not affect all genders equally. Through the embodiment of

dignity, capacity for self-determination and justice, individuals and their supportive communities will receive effective medical and psychological treatment to aid a lifelong journey of living with and managing autoimmune disease.

### **Personal Lens**

This research study was born out of pure curiosity, as I began making connections between my dual graduate degree programs. Clinical social work offered the emotional basis of well-being and holistic health studies brought the physiological underpinnings of health. The idea that the body does not recognize self as self was intriguing and troubling. After participating in a Family System Constellations therapy session at Pathways in Minneapolis, Minnesota, the mystery of this idea deepened. Each person carries things for his or her family. All these conflicting identities and enmeshments may contribute to the inability to have a clear self. Once the self is sorted out more precisely, the body may perceive threat and belonging differently. I discovered in *Heal Your Body* that the thyroid is linked to the emotional energy that I never get to do what I want to do and when is it going to be my turn (Hay, 1998). The energy related to the thyroid is linked to inner truth and the voice to express it, as well as personal choice and divine will. Difficulties in self-expression may include problems exerting the will to communicate one's true inner feelings and consciously recognize his or her own needs. People may lose sight of their own truth and begin to live by someone else's version of it. I saw my own experiences in Hay's reflections. These ponderings gave birth to this research study. My maternal grandmother has been diagnosed with Celiac disease, my cousin has Multiple Sclerosis and my 5-year-old niece is living with Type 1 diabetes. My story includes a journey through thyroid cancer during high school. During preliminary



development of this research proposal, I discovered thyroid autoantibodies were present in my blood before my thyroidectomy surgery in 1998. Slowly, over the past 14 years, my thyroglobulin antibodies have disappeared.

My personal lens provided the filter as I focused the scope of the research. I chose thyroid autoimmune conditions because I did not want to be perceived as an outsider probing into health concerns I have not experienced personally. The thyroid seemed fitting for a study on the relationship between autoimmunity, identity and community.

## **Literature Review**

The purpose of this chapter is to offer an overview of the published literature and scholarly articles relevant to the connections between identity, community and thyroid autoimmunity. A critical review of current knowledge lays the foundation for why further inquiry in this area of research is important.

### **Autoimmune Thyroid Illnesses**

The *thyroid* is a butterfly-shaped gland located in the neck area below the Adam's apple. Thyroid hormones play critical roles in the differentiation, growth, metabolism, and physiological function of virtually all tissues, directly acting on the brain, the gastrointestinal tract, the cardiovascular system, bone metabolism, red blood cell metabolism, gall bladder and liver function, steroid hormone production, glucose metabolism, lipid and cholesterol metabolism, protein metabolism and body temperature regulation (Shier, Butler & Lewis, 2007). Autoimmune thyroid illness is caused by lymphocytic infiltration of the thyroid which can result either in destruction of the thyroid, *Hashimoto's thyroiditis*, or in stimulation of the thyroid, *Graves' disease* (Cihakova, 2001).

Hyperthyroidism caused by the overproduction of thyroid hormones is responsible for the main symptoms of Graves' disease (Cihakova, 2001). Body metabolism is increased as autoantibodies against the TSH receptor (Anti-TSH-R) bind to and stimulate the receptor, causing a non-suppressible overproduction of thyroid hormone. Symptoms include goiter, protruding eyes, weight loss, increased appetite, diarrhea, rapid heart rate, emotional disequilibrium, heat intolerance, loss of hair, menstrual irregularity, feeling hot all the time. Treatment includes anti-thyroid drugs,

partial removal of thyroid through surgery or radioactive iodine therapy and beta-blockers.

Hashimoto's thyroiditis occurs when chronic inflammation, caused by an autoimmune process, destroys the thyroid gland, leading to hypothyroidism, an insufficient production of thyroid hormones (Cihakova, 2001). Common symptoms include fatigue, depression, sensitivity to cold, weight gain, muscle weakness, dry or brittle hair, high cholesterol, constipation, muscle cramps, increased menstrual flow and risk of miscarriage. Life-long thyroid hormone replacement is treatment for the resulting hypothyroidism.

An estimated 20 million Americans have some form of thyroid disease (American Thyroid Association, 2012). Up to 60% of these people are unaware of their condition. Hashimoto's thyroiditis is seven times more common in women than in men. One in eight women will develop a thyroid disorder during her lifetime (National Women's Health Information Center, 2010). These statistics of prevalence reveal a pressing need to understand the mechanisms of endocrine autoimmune diseases. Anxiety and depression, two symptoms of unregulated thyroid conditions, are directly tied to mental health.

Gluten intolerance, vitamin D deficiency, supplemental iodine, blood sugar imbalances, adrenal stress and a leaky gut may all play a role in perpetuating autoimmune disruptions of thyroid function (Kresser, 2012). Autoimmune thyroid disease has also been associated with a variety of infectious agents, including Rubella, Epstein-Barr virus, retroviruses, Influenza B virus, Coxsackie virus and Yersinia pestis (American Thyroid Association, 2012). Nicotine increases the synthesis of T3 from T4 in the brain, while

alcohol and opiates block the breakdown of T3 in the brain. Because estrogen partially blocks the efficiency of thyroid hormone, women compensate by producing more than men, which may explain why women have larger thyroids and are more prone to thyroid disease of all types. Pollutant chemicals like polychlorinated biphenyls (PCBs) and dioxins have been shown to interfere with thyroid function (AARDA, 2012). Soy, corn, and brassica plants (e.g., cabbage, broccoli, Brussels sprouts) produce natural goitrogens that interfere with the body's uptake of iodine (Kresser, 2012).

### **Concept of Self**

*Self*, the answer to the question “who am I?” is a complex, multidimensional reality with several components. Self-concept, self-image, self-esteem, self-worth, self-respect, self-identity have all been words used to try to grasp this mysterious idea. Current theory and research conceptualize the human self-concept as a contextualized and dynamic cognitive structure with important adaptive and self-regulatory functions (Baumeister, 1998; Brandtstadter & Greve, 1994; Higgins, 1996; Markus & Herzog, 1991; Markus & Wurf, 1987). This conceptualization implies that individuals' self-concept is seen as an “organized knowledge structure that contains traits, values, episodic and semantic memories about the self and that controls the processing of self-relevant information” (Campbell et al., 1996, p. 141).

Boss, a leading grief and loss theorist, defines identity as knowing who one is and what roles one will play in relation to others in the family and community (2006, p. 115). It is confidence and clarity in one's inner continuity amidst change. As people mature, they revise their identities to bring their perceptions of who they are and their standards of who they should be into alignment.

To be truly human, a person must be given the opportunity to discover his or her own identity and to have it, to the furthest extent possible, acknowledged by others (Taylor, 1994). Through interactions with their environments, humans become co-aware of the world, developing self-awareness within the context of others (Rochat, 2003).

Hegel's Master/Slave model (1977) suggests that it is through recognizing and being recognized by the other that one become aware of one's own self. Self-consciousness depends on the other. Identity is dependent on the recognition received from others. Yet, self-consciousness does not lose itself in the other or to the other. If this were so, then one would no longer see the other as a self at all, but rather, merely see oneself in the other. In order to be certain of oneself, the other must continue to exist.

The other serves many functions in identity creation. Psychodynamic attachment theorist Lofland proposed seven forms of attachment with others that support the development of self: bonds with those who are role partners, those available to help with mundane tasks, those confirming cherished images and conceptions of self, those supporting assumptions about social reality, those joining to create useful myths and narratives, those who act as links to members of a social network, those with whom a vision of a shared future is constructed (Forte, 2007).

When an environment does not recognize a person's being and selfhood, Linehan (1993) refers to this as an invalidating environment. Private experiences are punished or trivialized, expression of negative emotion is not appreciated and painful emotions are disregarded. Descriptions of one's self are not accepted by the environment as an accurate self-description. When an invalidating environment does not appreciate one's

behavior as a valid response to events and often criticizes or punishes the individual self-regulation, self-concept and self-differentiation are negatively affected

**Self-Differentiation.** *Differentiation of self* is the personality variable most critical to mature development and the attainment of psychological health.

Differentiation of self is defined as the degree to which one is able to balance emotional and intellectual functioning as well as intimacy and autonomy in relationships (Bowen, 1978).

Differentiation of self refers to the ability to experience intimacy with and independence from others. Differentiation allows for flexible boundaries that permit emotional intimacy and physical union with another without a fear of merger. Five statements of self-differentiation include: I am self-validating instead of depending on other validation; I have the ability to self-soothe; I maintain a non-anxious presence in the company of another anxious person; I have a clear sense of self in close proximity to other; I tolerate pain for growth (Dailey, 2009). Flexible, adaptable, and better able to cope with stress without being overwhelming, more differentiated individuals operate equally well on both emotional and rational levels while maintaining a measure of autonomy within their intimate relationships.

### **Self-Differentiation, Stress and Health Outcomes**

Multiple research studies have confirmed Bowen's theory that people with chronic illness have levels of differentiation that fall short of what is needed to handle the chronic stress and anxiety in their lives. Showers et al. (1998) found under certain life circumstances a highly compartmentalized organization of the self-concept is likely to break down, whereas an integrated organization is more likely to withstand stressful

situations and to buffer against the adverse effects of life stress. Murray, Daniels and Murry (2006) explored differentiation of self, perceived stress and symptom severity among patients with Fibromyalgia. Strong healthy families were found to be a protective factor in stress and disease. Higher levels of perceived stress correlated to higher levels of symptom severity in patients while high levels of self-differentiation lowered symptom intensity. Hughes (2009) studied rheumatoid arthritis patient's perception of acupuncture treatment. Perceptions of self-worth, improvements in self-image, feelings of well-being, stabilized emotions, reduced levels of stress, relaxation and calm, feeling normal again and regaining their lives were all reported by the patients, pointing to the link between well-being and self-concept. Vuckovic, Schneider, Williams and Ramirez (2010) carried out the first clinical trial of women of shamanic healing for Temporomandibular Joint Disorder pain. Although participants described physical changes, three times as much written qualitative text was developed to changes in self-awareness, capacity of coping, improvement in relationships and taking better care of themselves. These research studies reveal that emotions, identity and stress are connected in the disease process.

### **Stress, Mental Health and Autoimmunity**

Mood disorders and stress are frequently associated with subtle dysfunctions of the hypothalamic-pituitary-thyroid axis (Rubino, 2004). Using longitudinal data from the Averse Childhood Experiences Study (ACEs) and hospital discharge records, the relationship between childhood trauma and the risk of 21 different autoimmune diseases were examined (Dube, 2009). As the number of ACEs increased, the likelihood of hospitalizations with any of the 21 diseases also increased. The relationship was stronger among younger adults.

Stress scores of life events correlate significantly with serum TSH receptor antibody activity (Fukao, 2003). The scores of daily hassles and problems in life were significantly greater in relapsed Grave's disease patients. Following a routine hospital visit, Grave's disease patients rendered euthyroid after 2-5 years of antithyroid drug therapy were asked to fill out questions containing measures of psychological factors. When patients were divided according to Grave's disease prognosis (41 with relapse and 28 with remission), four personality traits including hypochondriasis, depression, paranoia and psychasthenia were common in the relapsed group.

Autoimmune disease often co-exists with mental health disorders. Patients with Hashimoto's thyroiditis frequently present with symptoms similar to psychiatric disorders: a chronic insidious change in personality manifested by lability, anxiety or withdrawal; a gradual progressive depression; paranoid schizophrenia, psychotic depression or manic depressive disease (Hall, 1982). A large multicenter study found the presence of thyroperoxidase antibodies (TPO-Abs), indicative of autoimmune thyroiditis in 28% of DSM-IV bipolar patients (Rubino, 2004).

People with a history of one or more autoimmune diseases have a 45 % higher risk of schizophrenia (Eaton, 2006). In addition, patients with schizophrenia had a higher lifetime prevalence of nine specific autoimmune disorders, including Grave's disease, Celiac disease and chronic active hepatitis. Parents of the schizophrenic patients had a higher prevalence of 12 specific autoimmune disorders, including Grave's disease, Hashimoto's thyroiditis, Celiac disease, type 1 diabetes, rheumatoid arthritis.

At the Psychiatry and Psychology Department at the University of Gottingen, Germany, files of in patients with schizophrenia, affective or schizoaffective disorders



were retrospectively evaluated between January 1994 and May 2000 (Denger, 2001). Of the 1,782 in patients with acute psychosis, 109 patients had pathological thyroid findings. Twenty patients had autoimmune thyroiditis and most of these patients were also diagnosed with a recurrent major depression. There was no higher prevalence of autoimmune thyroiditis in affective disorders than in the general population.

### **Research Question**

As autoimmune diseases remain a hidden epidemic, understanding the mechanisms behind the body's protective, self-regulation break down is underdeveloped. Environmental exposure and genetic susceptibility do not fully explain the rise in prevalence of thyroid autoimmune diseases. Not everyone who is genetically predisposed or environmentally exposed develops an autoimmune condition. Likewise, every person with an autoimmune disease does not have strong genetic or environment risk factors. Current medical understanding speaks of a self-attacking mechanism, yet language of recognition may be a better fit.

As the literature review revealed, relationship is vital in reaching a state of balance and homeostasis, and yet, each person must have a defined self, a congruently storied self, in order to healthily interact. In order to define oneself, a person must be relational, recognized by another. Stress and heightened immunity activity results from a lack of self-differentiation and social support.

When people are unable to recognize their self, or their environments are unable to see them, this misrecognition may be mirrored in the body's failure to distinguish self and non-self cells. Mental autoimmunity, the inability to emotionally and spiritually recognize and voice the story of self, may play a role in a person's susceptibility to thyroid autoimmunity. This study is interested in how participant lives, sense of self and relationships to others are experienced within thyroid autoimmune illness. The research question explored in this arts-based, phenomenological research study is: What is the lived experience of people living with thyroid autoimmunity and their relationship with self and others?

## Methodology

The purpose of this chapter is to describe in detail the methods used to conduct this research study on the lived experience of people living with thyroid autoimmunity and their relationship to self and others. Research design, data collection and analysis, instrument creation, as well as protection and recruitment of participants will be discussed.

### Research Design

The purpose of this research is to explore the connections between identity, community and thyroid autoimmunity through arts-informed qualitative investigation. Qualitative research is a form of social inquiry focused on the way people interpret and make sense of their experiences and the world in which they live. Within qualitative methods, the *phenomenological approach* attempts to describe and discover the meaning of lived experiences of a phenomenon by human beings (Lester, 1999). Researchers are most interested in how humans place themselves in their environments and how they make sense of themselves and their surroundings using symbols, rituals, social structures and social roles (Berg, 2009, p. 8). Phenomenological designs are valuable for research that seeks to delve in-depth into complexities and processes of little known phenomenon (Marshall & Rossman, 1999). Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation (Lester, 1999). The stories of people living with autoimmune illnesses provide rich data for exploring and understanding the connections between identity, community and illness.

A modified version of *PhotoVoice* was chosen as the research design. In the early 1990s, Dr. Caroline Wang, a professor and researcher at the University of Michigan's School of Public Health, developed PhotoVoice (Wang, 1999). It is a creative approach to participatory action research. Using community-based research activities, PhotoVoice is a method designed to empower members of marginalized groups to work together to identify, represent and enhance their community through a specific photographic technique (Wang and Burris, 1997). PhotoVoice allows participants to use visual images and accompanying stories to represent their own lived experiences rather than having their stories interpreted and told by others. This creative method of collecting information allows the researcher to see the participants' lives through their own eyes.

### **Data Collection**

I collected two kinds of data for this project: photographs using PhotoVoice and written reflections in project notebooks with a set of open ended questions. Participants were given a disposable camera and a project notebook which included a detailed list of instructions and a short eight question demographic survey (see Appendix C). The project was approved by the University of Saint Thomas' Institutional Review Board (IRB). Participants were given two weeks to complete the project in March 2012. After they finished, a short meeting was arranged at a coffeeshop or place of employment to collect the camera and notebook.

### **Instrumentation**

As the researcher, I created the project notebook. I was intentional about the questions I chose to include in the project notebook. At first, I hoped to narrowly focus on questions that would explore the validity of my theory of recognition. I decided to

broaden my approach and allow for a well-rounded view of the participants' life. I drew from my personal experiences, my educational background and questions I have asked clients in therapy. I unpacked what lived experience, identity and social connection might look like in someone's life. Lived experience was expressed in questions about what healthy looks like, a favorite, meal, how thyroid illness has affected one's life, where medicine is kept, stress and anxiety. I desired to learn how nutrition was connected to illness. I wanted to know how the participants imagined health. I hoped to find out how many medications they were taking. Questions about identity were held in how one spends energy, a place of safety, a signature, going out and staying in clothes, happiness, life roles of value and invisibility, dreams and passions. I wanted to know how the participants saw themselves. I desired to learn if they clothed themselves in masks. I hoped to see their level of self-awareness and self-acceptance. Connection to other was embodied in questions about a confidante, a community of belonging, love, empathy and family. I desired to see how they exchanged with their world. I hoped to learn how readily they connected to other people in their life. Four pictures were reserved for anything additional the participants wanted to share with me.

The participants were given the opportunity to take 23-27 pictures of certain aspects of their life. After they took each picture, there was space provided to write down reflections about thoughts, feelings or stories tied to the picture. I wanted the image and their own reflections on what was happening in the picture. At the end of the project, there were two short reflection questions about what they learned about themselves and how they interact with their environment. I included a short demographic survey, with questions about age, gender and diagnosis. I desired to learn the context of their disease.

In order to gather this information, I asked about life events and symptoms that occurred at the time of diagnosis, the places they have lived, co-existing illnesses and family history of autoimmune disease.

### **Reliability and Validity**

Quality, credibility and reliability of this research were enhanced by transparency and disclosure about the ways my subjective experiences, biases and assumptions influenced the research. A clear description of the process I used is provided throughout the paper to demonstrate the rigor of the study. My instruments are included in the appendices to allow for replication and adaptation.

Reliability was strengthened by incorporation of feedback from social work, holistic health and research professionals into my research. Validity and trustworthiness of the study were reinforced by my on-going reflection about the data and research process in field notes and conversations with professionals. In this creative-arts, phenomenological study I honored the harmony and connection between the purposes, processes, orientation, literature and outcomes of the study (Coles & Knowles, 2008).

### **Recruitment of Participants**

Along with the selection criterion of a current thyroid autoimmune illness (Hashimoto's thyroiditis or Graves' disease), three factors influenced the choice of a 25-66 year old age range for participants. The Differentiation of Self Inventory (DSI) developed by Skowron and Friedlander (1998) was a self-report instrument for adults over the age of 25. Erikson's Stages of Development (1959) place the basic task of identity versus role confusion during ages 12-18 and intimacy and isolation during ages 19-40. Given this study's focus on identity and being recognized in relationship, age 25

comes after identity development and in the middle of developing connection. The upper limit of 66 was chosen because autoimmune diseases are a leading cause of death for females ages 1 to 65 (Walsh & Rau, 2000).

Participants were recruited through non-probability, purposive sampling. A flyer was posted on public bulletin boards at local coffee shops, community centers and health clinics in Saint Paul, Minnesota (see Appendix B). No response was received from potential participants. The information on the flyer was converted into an announcement for the University of Saint Thomas' daily news feed. The day it was posted over a dozen people responded by email or phone. All potential participants were given further information about the study. Several participants did not follow up with a response. After screening for the age and thyroid autoimmune condition criterion, eight participants were accepted into the study.

### **Protection of Human Participants**

Protecting human participants from harm or unethical practices was an important consideration as I designed and carried out the research. Informed consent, confidentiality and anonymity were priorities during the Institutional Review Board's approval process.

**Informed consent.** Participants met with me for an informational session at local coffee shops and places of employment. Prior to receiving the project notebook and disposable camera, the study participants signed a consent form approved by the University of Saint Thomas' IRB in order to ensure respondent protection (see Appendix A). The consent form outlined why the participant was selected for the study, information about the researcher and the purpose of the study. The form also addressed

the procedures involved in completing the PhotoVoice project, including who has access to the research data, the risks and benefits of participation in this study, the voluntary nature of the study and consent to participate.

**Confidentiality and anonymity.** In all data transcription, analysis and dissemination, all identifying information for each participant (e.g., names, locations, job titles) was removed. Pseudo names were chosen and assigned by the researcher. In all public use of data, including disclosure to the chair, committee members, those present at the public presentation, as well as those who read the published paper, all faces were blurred in photos and all identifying information was deleted from written material.

In accordance with law, participants agreed to not taking pictures that contained nudity, were graphically physically revealing or were of children in private settings who were not their own children. All photos were developed onto a CD. No loose prints were created. All data and research information, including photo CDs and notebooks were stored in a locked file cabinet and password protected files on the researcher's personal computer. No data identifying the subjects was available to anyone other than the principal investigator. Participants received a personal scrapbook containing their personal photo and written contributions, as well as the study results. Deidentified photos and notebooks will be kept to inform future research.

### **Data Reduction and Analysis**

The process of sorting through and making meaning of the data I received was time-consuming and overwhelming. I was surprised by the richness and quality of the stories and images. I received all eight notebooks between the end of March 2012 and early April 2012. The photo developing was delayed slightly because of technical



glitches. First, I read all the written data together. I then read each of the participant's stories separately. Next, I looked at all the pictures together. I then reviewed each of the participant's photos separately. The fifth time with the data, I read the participant's words while looking at the image included. I did not always see a clear connection between the photo and words. This surprised me. Through each of these rounds of reading and observing, I did not draw any conclusions. There were hundreds of interesting pieces of data to explore and connect. They differed in their relevance to my specific research purposes. In order to manage the volume of data, I chose three categories that aligned with the research questions of lived experience, self and connection to other. In the final round through the data, I pulled individual quotes that fit into each category. The development of categories or codes allows the researcher to link or ground the themes to the data from which they are derived (Berg, 2009). As I sat with the data, I realized that it would be difficult to use Grounded Theory, a qualitative analysis approach, to analyze the data.

During discussions at my committee meeting, it became apparent that narrative analysis fit with my PhotoVoice methods. Narrative analysis focuses on the ways in which people make and use stories to interpret the world. Narratives are viewed as social products that are produced by people in the context of specific social, historical and cultural locations. Story is the interpretive devices through which people represent themselves and their worlds to themselves and to others. In analyzing narratives, the researcher works to actively find the voice of the participant in a particular time, place or setting (Connelly & Clandinin, 1990).

A typical narrative framework focuses on the core narrative or basic plot through four categories: an orientation describing the setting and character, an abstract summarizing the events or incidents of the story, a complicating action which offers an evaluative commentary on events, conflicts and themes and resolution or outcomes of the story or conflict (Mishler, 1986). Past and present experiences, as well as future intentions are explored within this narrative framework. Each of the participants addressed the context and setting of their story (thyroid autoimmune illness), pertinent characters (themselves, co-workers, family, friends, doctors), events and conflicts tied into their journey through illness (loss, spirituality, vocation, body changes, symptoms) and outcomes (growth, anger, confusion, gratitude, reflections on what they have learned, future dreams).

## **Findings**

This chapter describes the results of this arts-based, phenomenological research study about the lived experience of people living with thyroid autoimmunity and their relationship with self and others. The demographics of the participants are given. In order to honor the voice of each participant, I provide individual case stories, weaving together images and written reflections as they pertained to lived experience, story of self and connection to other.

### **Participant Demographics**

The demographics of the participants were collected in a short eight question survey at the end of the project notebook. One male and seven females, between the ages of 40 and 66, participated in this study. Four participants were living with Hashimoto's thyroiditis and four participants were living with Graves' disease. Seven of the participants resided in Minneapolis, Saint Paul or within the Twin Cities' suburban area. One participant lived in Minnesota. Apart from one participant's diagnosis of Celiac disease, no other autoimmune conditions co-existed with the thyroid autoimmunity. Family history of autoimmune conditions included hepatitis, thyroid disease, Sjögren's Syndrome, Rheumatoid Arthritis, Diabetes and Celiac disease. Several participants had unknown family histories. Two participants briefly commented on life events that occurred around the time the symptoms began: the birth of a child and a new job.

### **Story One: Skye**

Skye is a female in her mid 60's who has been living with Hashimoto's thyroiditis for over one year. She has no family history of autoimmune conditions. She first experienced thyroid dysregulation after her son's birth in the 1970's. Over her lifetime,

Skye has resided in over 20 cities throughout the world. After many years of low-energy while living in Minnesota, she had her thyroid levels retested in 2011 and the doctors discovered her autoimmune condition.

Living with a thyroid autoimmune condition has shifted many things in Skye's life. She acknowledges that her illness has shaped and reshaped many of the roles she embodies on a daily basis (see Figure 4).

*Everything in my life is affected by this diagnosis. I have no energy most of the time. When you have no physical energy, it is easy for doubt, fear and depression to enter in. I'm tired in this picture. I want to always rest or do something easy. Challenges are not part of my life. I don't feel capable of being successful with them nor do I feel smart enough, good enough, strong enough. I feel successful with my yoga practice most of the time because it's all about letting go of tension. I'm always trying to do that, to let go of all things which keep me from God so I can transform and live as my True Self.*

In the midst of struggling with the effects of her thyroid symptoms, Skye experiences a deep connection to her husband (see Figure 5).

*I feel most valued in my role as wife and marital companion. We are also mutual spiritual seekers on the same path towards spiritual enlightenment. He's the only one, though, who sees the real me – the good, the bad and the ugly – and loves me unconditionally. This is one of our wedding pictures – my favorite because we're looking at each other and not the camera. I can feel in this picture our love for each and our mutual respect for each other. My husband is also my best friend, one whom I do not feel invisible to.*

Apart from her connection to her husband, Skye experiences a high level of invisibility in most of the roles she finds herself within (see Figure 6).

*This is hard for me to choose one because I feel invisible in my life, period, expect for with Brad. But I'll pick my children. You can see that I am not in this picture because I feel invisible to them. I suppose most parents feel that way after their children grow up but I do feel ignored by them. My birthdays come and go and I get no gifts, no cards. I am lucky if I get a call.*

Finding her own voice and seeing herself as someone worth listening to has been an ongoing quest in Skye's life journey.

*I didn't really accept the fact that this feeling invisible thing is so strong with me and pretty much is involved in all of my roles and dealings with others, even in those where I am a participant. I have a hard time speaking up and sounding intelligent when I finally do get a word in. I always feel inferior to others and never come across as "the knower" telling others this is the way. Now this is interesting because with my yoga training I am able to do just that – tell other how to do something. But that's the only area in my life when I do that. Outside of yoga where I've been trained on what to say and have developed my own way of teaching and outside of storytelling in which I memorize certain words and the flow of the story, I cannot command anyone to listen to me.*

In addition to yoga and storytelling, being with the natural world allows Skye to feel comfortable and welcomed (see Figure 7). She can be herself with no expectations. She has brought the safe part of nature into her home (see Figure 8).

*This is the first thing I see when I walk in from the garage into my home. It is my safe place, my haven. I have tried to create a sweet, beautiful, very comfortable garden-like atmosphere to enter when I come back to it leaving the outside world behind me. When I come through the door, I sign and say, "Hi home" and all tension is obsolete in real energy of my home. Nature is very important to me. It energizes me, rejuvenates and relaxes me at the same time. It accepts me, opens to me. I don't have to think, speak or act in Its presence. It is simple and demands nothing of me except my awareness. I admit, though, that I could not be out in a wilderness by myself and survive. I would be filled with fear. So I guess I enjoy and appreciate it only from where I am comfortable and safe with It.*

Skye feels stuck living in an in-between, not yet arrived state of being. She describes herself as a child who has an all-knowing woman of Light inside (see Figure 9).

*Most of the time I wonder if I ever grew up. I feel like a child but then again I feel like an exquisite, all-knowing woman expressing my Divinity. To me it either represents who and how I'd like to be or it does represent who and how I am... I know that I have something special within me, that I am a daughter of radiance. I just have not been able to live it yet or perhaps I don't believe it yet.*

This duality is revealed in her signature. Skye signed her name twice, in the middle of the piece of paper at a 45 degree uphill angle.

*I signed it twice cause I didn't like the first W with that little squiggle in the first loop. OK, so I can be a bit of a perfectionist sometimes. As I signed I was nervous about making a mistake and I did. I self-prophecy a lot with my fears.*

During this project, Skye discovered much insight into the tension of knowing herself, her truest self, more fully.

*What I've written about here in this project only supports what I already know about myself. I have no pizzazz usually, no energy which makes fear, anxiety and stress and depression easier to enter into the picture. I don't attempt new things on my own unless I'm asked. I need an advocate to promote me and support me and do the foot work and the technical stuff. My emotions get the best of me. I do have some special gifts though that help bring me into the present like my writing. Even though I deal with low self esteem, when I write I feel unique and like I'm accomplishing something important. I found this project brought me into a satisfying intimacy with myself. It was almost a purging to actually "write myself." I know these things about myself but a new dimension was added when I took a picture and then wrote about myself. Very powerful. I feel a new sense of control and power. My dreams last night did not have their usual frustration underlying their contents. Instead the symbols were lofty like trees and birds and I was interacting with them as a whole being experiencing wisdom and a sense of purpose. Usually I awake feeling agitated about dreams that I don't remember. This morning I felt refreshed and calm.*



Figure 4. Skye's picture of the role most affected by her thyroid condition.



*Figure 5.* Skye's picture of a role in which she feels most valued and appreciated.



*Figure 6.* Skye's picture of a role in which she feels unsupported or invisible.



*Figure 7.* Skye's picture of something that makes her smile.



*Figure 8.* Skye's picture of a place where she feels safe.



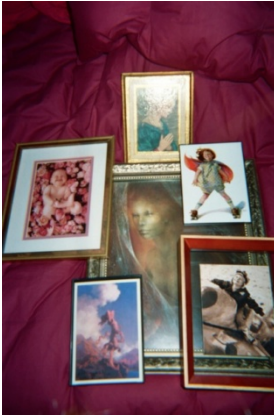


Figure 9. Skye's write-in-her-own photo.

### Story Two: Christine

Christine is a female in her early 40's who has been living with Graves' disease for over 15 years. Her symptoms, a shortened attention span, an inability to sleep and manage her money, began a year before her diagnosis. She has a family history of thyroid and hepatitis autoimmune conditions. Christine has lived in more than five cities throughout Minnesota.

Christine's view of herself and her symptoms shifted as she moved through diagnosis (see Figure 10) and sought treatment (see Figure 11).

*Before I was treated I was unable to sleep. It was like my on/off switch was stuck ON. I got severe mono, strep throat, etc because I couldn't get the rest I needed.*

*Now I sleep 6-7 hours a night. It's awesome!*

*This is the hardest question to answer. I think it affected all my roles in a subtle way. I took a photo of a piece of art by my friend. The woman in the center of the picture has a peace lily as a spine. I feel more like that since my condition is under control.*

Christine family (see Figure 12) has been a source of connection, hope and support during her journey through Graves' disease (see Figure 13).

*My sisters are both awesome. I have the kind of family others want. This is a picture of my sister. She has seen me through everything and has never judged me. She is the most loyal person I know.*

*OK, so this might seem strange. It is a picture of my dad. We (my parents and I) were talking about this study. When I asked them what healthy looks like, this was my dad's response. He is a 65 year old organic sheep farmer, who cannot taste or smell. Besides suffering from PTSD from war, my dad is a drinker.*

Finding her place in the world has invited her into moments of invisibility. She hopes to find a career where she'll be able to express herself more authentically (see Figure 14).

*Being a writer is often an invisible job. There are a lot of days I feel forgotten by the rest of the world. That's exactly why I am going back to school for my Master's degree. I need a more extroverted profession.*

What she projects to the outside world doesn't always match what she feels on the inside. Christine's signature is written vertically down the middle of the page, with equal empty space on each side of large, flowing letters.

*My signature looks far more sophisticated and put together than I feel.*

Completing this research project brought up new feelings and insights about how she sees herself and her comfort with being seen.

*I don't like examining myself through a lens. Didn't know I'd have hang-ups about it. I've always had weight issues. When I got Graves I lost 60 lbs without*

*trying. Since they got my thyroid under control, my weight has steadily climbed for 14 years. Last May, I had gastric bypass. I have lost 120 lbs and feel pretty good. I still don't like being photographed though.*



*Figure 10.* Christine's picture of how Graves' disease changed her life.



*Figure 11.* Christine's picture of the role most affected by her thyroid condition.



*Figure 12.* Christine's picture of a confidante in her life.



*Figure 13.* Christine's picture of what being healthy looks like for her.



*Figure 14.* Christine's picture of a role in which she feels unsupported or invisible.

### **Story Three: Ash**

Ash is a female in her late 40's who has been living with Graves' disease for 5 years. She also cannot eat gluten because of Celiac disease. At a regular annual physical, her doctor noticed an enlarged thyroid. Her family history of autoimmune conditions is unknown. Ash has lived in more than five cities throughout the United States.

Ash's experience of Graves' disease has influenced how she sees herself (see Figure 15) and how she imagines health (see Figure 16).

*My best friend in the world gave me this basket. I love the colors, the monogram and the 'southernness' of it. So I use it to hide and hold my extensive pill collection – I worry that I take too many things already and I'm so "young." (I know, I'm not that young, but still...) Some of the pills are vitamins or Chinese*

*herbs so I do feel like I am doing a good job taking care of myself. I am very good about remembering this part of my self-care routine.*

*This girl is on the cover of the box of my exercise rope thing in it. I wish I looked like this. I feel so fat and so opposite of it. (Note: I had to dust the top of the box so I could take the picture. If it was less dusty and out of the box, that might be a good start). Ugh.*

Apart from daily doses of medicine, regular self-care allows Ash to feel happy (see Figure 17), safe (see Figure 18) and cared for as she manages to readjust to her ever-changing story of health.

*I love to bead and make jewelry. I love looking at all my “stuff” – the colors, the cool tools – it all makes me happy. I am not that creative but I can copy ideas and figure out a creative way to make something similar. Usually, I am making things for myself which feels a little selfish, but...oh well.*

*Both of these locations are places where I feel safe to be me. I don't feel judged. I feel cared for and mothered. I love the serenity, the music, the caring and gentle touch, the lighting, the feel of the firm bed under me – just everything. But mostly, I feel safe and cocooned.*

Ash's connection her husband Joe (see Figure 19) and son John (Figure 20) have enabled her to experience acceptance, love and support as she has journeyed through her illnesses.

*Joe is my 2<sup>nd</sup> husband. More than anyone else, he seems to accept me for who I am. I feel like I can be myself – no pretenses and no games. I love that he took me and all my baggage into his life. He's seen me dealing with work stress, ex-*

*husband stress, parenting stress and perimenopause. He's still here. He went through the thyroid stuff, Celiac disease, Dad's death and Mom's treatment. He's still here, so I trust him.*

*Joe took this picture of me with John after his game. I know he likes me being there and he does seem to appreciate the money sacrifices I've made so he can do sports. He hugged me and let me kiss him...in public. That's how I know I'm important.*

Although she has great relationships with her co-workers and boss, Ash does not feel fully supported and valued in her professional role at work (see Figure 21).

*I feel invisible and unsupported by my company – at large. I know changes to the organizational structure are coming and I'm concerned that people who don't know me will be deciding my future. That really bothers me.*

Knowing exactly who she is and integrating the changes in life into her story has been challenging for Ash. Her signature was centered on the page, slightly angled uphill.

*This was my name for 23 years and then it wasn't for 15. It's been my name again for 6 or 7 years. When I write it, I have to think for a split second.*

*Sometimes I'm reminded of my mistake and divorce. But mostly I like my name and my signature.*



Figure 15. Ash's picture of where she keeps her medicine.



*Figure 16.* Ash's picture of what being healthy looks like to her.



*Figure 17.* Ash's picture of how she expresses her passions and giftedness.



*Figure 18.* Ash's picture of a place where she feels safe.



*Figure 19.* Ash's picture of a confidante in her life.



*Figure 20.* Ash's picture of the role in which she feels most valued and appreciated.



*Figure 21.* Ash's picture of a role in which she feels unsupported or invisible.

#### **Story Four: Alice**

Alice is a female in her early 60's. Fatigue was the symptom that preceded her diagnosis of Hashimoto's thyroiditis. Date of diagnosis was not given. Her family history includes Sjögren's Syndrome and thyroid autoimmunity. Ash has lived in more than five cities throughout the United States.

Living with Hashimoto's thyroiditis has affected how she sees herself and the responsibility she has to be in this world as she desires (see Figure 22).



*Me – being myself. Self portrait. I am responsible for how/what I eat. I believe my thyroid condition has little to do with my eating habits or my weight. The one way Hashimoto’s has changed my life is that I am “obligated” to take thyroid meds from now until forever. Forever is a long time – what would happen if I was stranded on a desert island?*

Alice’s story of self changed after a divorce in her past. In the midst of the shifts in family structure, she still finds safety (see Figure 23) and love from her family, her daughter (see Figure 24), granddaughter and dog.

*My name has changed. Divorced many years ago. I like my signature [signed at the bottom of the piece of paper, slightly to the left side].*

*It’s my bedroom – my dog is on the bed. It is a room where I feel safe and comfortable – my bedroom is where my granddaughter loves to be – she watches her movies on my bed – I keep her safe here. My dog is my constant compassion – she makes me feel safe and secure.*

*My Daughter. She is the person with whom I am most honest. I think back about all we have been through – where we are today. She is love. I remember her in the difficult years when she never wanted her picture taken and always wanted to be somewhere else.*

As Alice looks into the future, her dreams include expanding her side business so it can flourish financially, supporting her, her daughter and her sister (see Figure 25).

*This is a picture of our logo. We have a small floral business now – would love to “grow it” large enough to support me. My daughter/my sister. Maybe turn it into a store front too!*



*Figure 22.* Alice's picture of the role most affected by her thyroid condition.



*Figure 23.* Alice's picture of a place where she feels safe.



*Figure 24.* Alice's picture of a confidante in her life.



Figure 25. Alice's picture of a future dream or goal.

### Story Five: Maggie

Maggie is a female in her early 40's who has been living with Hashimoto's thyroiditis for over two years. After beginning a new job position, symptoms of dizziness and fainting began. After a long process of testing with multiple doctors, Maggie's dosage of medicine and blood levels are finally regulated. Her family history includes thyroid autoimmunity, Rheumatoid Arthritis and Type 1 Diabetes. Ash has lived in two cities in Minnesota.

A life lived with thyroid autoimmunity shapes Maggie's daily routines (see Figure 26). Stretches of exhaustion and moments of frustration and fear are overlaid with a deep sense of gratitude (see Figure 27).

*The way Hashimoto's Disease has changed my life is that my energy level is not what it once was. After a long and busy day at work – some nights the comforts of this cozy chair and either a good book, phone call with a friend or TV show are all I have in me. I try to get things done around house at night, and ideally get in a walk, but some days my energy level is just zapped and I relax in this great chair, decompress and re-charge my energy for the next day.*

*This is my combination medicine/Keurig coffee drawer. I was so discouraged when my Endocrinologist told me I would be taking Levothyroxine for the rest of*

*my life. It also requires lab work each time I get a new refill. I consider myself lucky that this is all I have to deal with medically at this time. I know many people who have far more challenging and painful illness and diseases than I do. While it has been difficult during my diagnosis and the past two years adjusting/regulating my medicine dosages – it is definitely a disease I can manage and live with – and for that I am thankful.*

In addition to adjusting to life with a thyroid imbalance, Maggie has experienced stress from relationships, commitments, school and personality traits (see Figure 28). Her significant early loss of a parent creates a self-perception of being different and not fully understood by her peers (see Figure 29).

*These are a few words I selected that at different times in my life have added stress to my life.*

*I chose this picture as I have a role as a Fatherless Daughter – not a role I wanted to take on. My Dad meant the world to me and not a single day goes by where I don't think of him, or miss him. I chose this role because although I have wonderful, supportive friends – very few of them have lost a parent and as a result they can't fully comprehend what a tremendous void it leaves in your life. They are very supportive, and have been there for me, but it is still different in that for many of my friends it is not a shared experience and as a result it is a role they can't fully wrap their hands around at this time in their life. I hope they don't have to experience this role for many, many years. Nothing prepares you for losing a parent.*

In the midst of the stress and loss, Maggie finds refuge and comfort as she connects to her friends (see Figure 30) and a place of deep spirituality (see Figure 31).

*Courtney is very special to me. I was her Confirmation Sponsor and to this day we refer to one another as a “Spiritual Friend” a phrase we began from a Confirmation retreat we attended years ago. Courtney makes me smile because she is such a genuine person. She recently got engaged to her high school sweetheart. It makes my heart swell to see her so happy. She will make a wonderful wife, and the most beautiful bride you’ve ever seen.*

*This is a picture of my church. It is a place that is special to me, and a place I always feel welcome and accepted. Even if I happen to lapse in attending mass, I always feel welcome upon my return. I think it feels safe to me because it is a big part of my entire life.*



Figure 26. Maggie’s picture of how Hashimoto’s thyroiditis changed her life.



*Figure 27.* Maggie's picture of where she keeps her medicine.



*Figure 28.* Maggie's picture of stress.



*Figure 29.* Maggie's picture of a role in which she feels unsupported or invisible.



*Figure 30.* Maggie's picture of something that makes her smile.



*Figure 31. Maggie's picture of a place where she feels safe.*

### **Story Six: Jessie**

Jessie is a female in her late 50's who is living with Grave's disease. Date of diagnosis, other medical conditions, family history of autoimmunity and other demographic information was left blank. Her project was returned by email. Jessie typed her responses in a Word document with cut-and-pasted images she presumably found online. She included a few digital photos of her own.

As Jessie grapples with the effects of living with a thyroid autoimmune condition, her inability to see details clearly brings frustration into her professional role as an accountant (see Figure 32).

*If there is any affect from my diagnosis I would say reading the tiny print on spreadsheets as an accountant. Soon after my diagnosis I began to have trouble reading smaller numbers. My sight just wasn't as sharp as it should be.*

*Consequently as an accountant I have to constantly re-read the numbers I think I see when the print is small. As long as I have reading glasses I should be ok. The membranes behind my eyes started swelling just before I was diagnosed with Graves Disease. It never got to the point of protruding eyeballs but they became noticeable to others. As soon as I took Radio Active Iodine the swelling started to subside.*

Fear and anxiety tied to money spills over into her personal life. Jessie is often worried about the future and how her health will affect her future employability and security (see Figure 33).

*Anxiety for me is lack of money to pay my bills. I worry that there will not be enough money for me to retire on. I worry that I won't be employable later. I worry that I will have some big expense that will wipe me out. I worry that my health one day may cost me more than I have to spend. I am hoping that having had Graves disease didn't mess too much with my immune system so that I stay healthy in every other way.*

As Jessie contemplates her future and the health she desires, she acknowledges the changes in her body and holds to the hope that she will age vibrantly (see Figure 34).

*Healthy for me is looking fit and vibrant. As I get older I miss the ability to run like I used to. I remember all the old softball games and the days I used to Lifeguard and swim. My knees are bad now to the point of needing replacements and I am heavier but I do know that with exercises and healthier eating I can get some of that back again. It's in the commitment and I am more tired now than I've been when I was younger. I don't like the thought of becoming old...it's not in my mind.*

Many memories of judgment come up for Jessie as she reflects on her signature. She found her way of writing after many years of practicing other people's styles.

*I remember the nuns hammering a fat pencil on the top of my head when I didn't write correctly. They were all about penmanship and drilled us from second grade on. Writing is a normal thing for me as is being neat about my writing. My*



*dad used to challenge me on my writing as well. Sometimes he said it was too small and sometimes he didn't like the way I made certain letters. I remember seeing other people's writing and trying to mimic their styles as I practiced through the years. I finally settled into the style I have now in my signature. The only problem with it now is the osteoarthritis in my pinky fingers making it a little harder to write as nicely as I can. I am also very particular to certain types of pens to use for my signature as well. I don't sign well with fine point pens as they slide too quickly over the paper. I feel more secure with medium pens that have a broader and slower hand.*

Connection to others through roles as sister and mother brings joy and love into Jessie's life. She is frustrated that the support with her sister is not mutual (see Figure 35). An early loss of one of her sons brought deep sadness into motherhood (see Figure 36).

*This is my sister Jennifer. We weren't always close but over the last 30 or so years Jennifer knows things about me that no one else knows. She was with me through some very rough going and really got me through it. There were things I needed to discuss with someone other than my kids so they didn't worry. Her positive attitude and thinking helped me recognize when I had my "pity pants" on. I only wish she could confide in me and for some reason she doesn't feel like she can. I am conflicted on this part because I love her enough to want to be there for her and know I won't judge her ever either.*

*This is a picture of the most important people in my life. My boys. I love them unconditionally and I believe they love me back. I don't think people know a*

*greater love than that you have for your children. I say that because I unexpectedly lost a fifth son (who was in the middle) when he was 3 days old with a heart defect. Lost him on the operating table and it ripped my heart to shreds for a while. As a mom you feel such love immediately and you feel you should be able to save and protect them from anything. When you can't or you fail it devastates you for a while. I often said that I loved Scott the same at 3 days as 3 months, 3 years etc. It doesn't change for a mom.*



Figure 32. Jessie's picture of the role most affected by her thyroid condition.



Figure 33. Jessie's picture of anxiety.

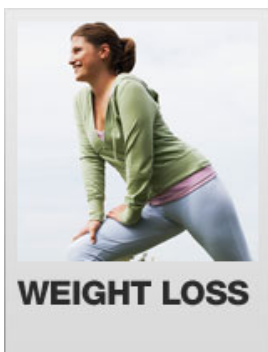


Figure 34. Jessie's picture of what being healthy looks like to her.



Figure 35. Jessie's picture of a confidante in her life.



Figure 36. Jessie's picture of love.

### Story Seven: Annie

Annie is a female in her early 50's who has been living with Hashimoto's thyroiditis for almost five years. Her symptoms began two years prior to the diagnosis. Her family history includes Celiac disease. Annie was born overseas and has lived in a dozen cities on both coasts and in Minnesota.

Basic daily routines, like getting dressed and eating, are deeply affected by Annie's journey through Hashimoto's thyroiditis (see Figure 37).

*A person has to get dressed every day...getting dressed is no fun anymore. On the left is my old jeans and tank top, which I would love to fit into again someday. On the right is my current clothing size and style and material. You know it is bad when you have a hard time finding sweatpants big enough!!! I included two bowls to show how much I typically ate. Yes, before I got sick, I could eat a large*

*bowl of whatever. Now I eat small portions and I still struggle with weight.*

*Being 80 pounds overweight is utterly...crushing. I look older than I am, can't fit into theater seats, etc...I hate it and doctors are not interested. I want my metabolism back!!!*

In the midst of trying to identify and treat the symptoms, Annie's professional and vocational role of piano tuner spun into chaos (see Figure 38).

*My piano shop...my business was almost destroyed...A lot of my identity is "being a piano tuner." I've never had another career. I have a lot of time and money invested in these tools and skills and experiences...and yet the "brain fog" as others have described it, almost wrecked my trade...I could not find customer's houses, even when I'd been there before. I lost customer's because of that and because my "tuning time" (speed of tuning) got so slow.*

Annie experiences a drain of energy when she engages with the outside world. A picture of the door was not included in her photos.

*This is the door our family uses most often. It's hard to go through it. I don't want to face the world outside. I want to stay in my house – I can clean, organize, even decorate a little. If I get courage I can check email or phone someone – it's safe here and I know I am "in charge" and there are no surprises. I do not want to leave. I have to give myself a "pep talk" to leave.*

Annie prefers an environment that is quiet and peaceful. She finds safety in her bedroom, a place where she controls the intimacy and level of connection. She wrote about her hiding place two times (see Figure 39).

*My bed. The bear I sleep with, my pillow, etc. When I am totally overwhelmed, this is where I go. Here it is safe and warm and hidden. The only people who come here are those I totally trust and there are no phones.*

*My bed – where I retreat when I am overwhelmed. It is safe and warm and nobody mean is there. There is no telephone, either! No TV broadcasting bad news, no bills – there I can read or sleep (or think, when I have the courage to think). Everyone needs a place to hide. I’m glad my place is so accessible to me.*

Because of Annie’s thyroid autoimmune condition, she is required to entrust her life to bottles of medicine. This brings up deep fear, insecurity and suspicion for her (see Figure 40).

*The two in the center are Rx’s and keep me alive. My life is in these bottles. That is scarier than hell. Many Rx’s are now made in foreign countries, like China. What else do they put in there, besides the medicine? What slow poisons (or cockroach eggs) may be included? The others are “OTC,” herbs, minerals that help hugely – but the doctors are not interested in those. The selenium especially, eliminates pain but doctors are never interested in my pain/muscle spasms or in what triggers it (foods high in Vitamin C) or how I treat it. I think most doctors want me to feel stupid.*

In the middle of the tension of whom and what to trust, Annie experiences confidence, love and support from her husband of 30 years. No photo of him was included.

*He's my husband and my best friend. He has seen me at my worst and still loves me. He still makes me laugh and he knows me better than I know myself. I like being with him. Everything is better when he's around and I feel more hopeful.*

Annie signed her name as declaration to the world that she wants to be known and understood. She is not invisible. She has something to offer others. Her signature was signed in brown marker, vertically on the page.

*There's a lot more to me than just my name. I used my nick name. I am accustomed to only hearing my full name when I am in trouble or being addressed by strangers. I want to be known and understood so I used my nickname. I don't want to be overlooked, so I used marker instead of pencil and I used the fancy little swirl (underneath) that my dad also used to use when he had written something special – because I am worth listening to. I try to make things better. 24/7 I am trying to help someone, neaten a place, encourage someone, fix something, pick up some litter, etc. I was raised to believe I am dirt, so I'm fighting my upbringing here...Give me a chance.*



Figure 37. Annie's picture of how Hashimoto's thyroiditis changed her life.



*Figure 38.* Annie’s picture of the role most affected by her thyroid condition.



*Figure 39.* Annie’s picture of a place where she feels safe.



*Figure 40.* Annie’s “write-in-her-own” picture.

### **Story Eight: Dustin**

Dustin is a male in his early 50’s who has been living with Grave’s disease for most of his life. Over ten years ago, his health began to deteriorate. He experienced depression, chest pounding, weight loss and tremors. He lost so much weight, he almost

had a heart attack. He was finally diagnosed with Graves' disease about four years ago. His wife's family has a significant history of Ulcerative Colitis. Dustin has lived in less than five cities throughout the Twin Cities.

Dustin signed his name twice on the piece of paper. The first is at the top, slightly smaller, in pencil. The second signature is larger, closer to the left margin, in the middle, in pen.

*I guess it's uniquely mine. I don't think about it much though.*

After years of a feverish life of intense extremes, treatment of Graves' disease allowed Dustin to regain a sense of balance in life (see Figure 41).

*Graves took away my strength for a while. I has returned. I am grateful for the balance I have been able to achieve in my life owed to the treatment of my disease. Finally having my hormones and nutrition in check has allowed me to manage and control (and live) my days to their fullest. Where as before I was simply burning up.*

As he reflects on his life prior to treatment and his life after his hormones balanced, Dustin realizes his perception of himself and others shifted. His empathy deepened (see Figure 42).

*I always thought who we were – busy, energetic, positive, healthy, happy – lazy, angry, depressed, anxious, unhealthy – were all of our own free will. It wasn't until my hormones were finally balanced, that my anxiety, nervousness, fearfulness and depression (and high metabolism) left me.*



*We may in fact “choose” to act and be of a certain mindset. But our hormones and their balance within us determine whether our efforts to be who we wish to be come easily from within – or only after a struggle against our natural inclines.*

As Dustin walks through his journey of health challenges, he receives support and a sense of safety from spirituality (see Figure 43) and a long-time colleague and friend (see Figure 44).

*I have been to and feel comfortable attending services from most all faiths but I find peace and feel most safe when I at this church. Most of the families I knew when I was young have moved on – but I carry memories of years past, of baptisms and first communions and prayers of healing. I can go here all by myself and feel safe.*

*This is a picture of my friend Eric. I have known him for many years, for almost 30 years. We’ve talked about everything from our jobs to our children to our health. I feel probably more comfortable sharing with him issues in my life than my own brothers. I am not afraid to be real and genuine with him. I think he was surprised when I asked him to take the photo but when I explained he understood and appreciated how much I appreciated him.*

Dustin and his wife have three sons. His role of father brings him appreciation and value, as well as a sense of loss and invisibility (see Figure 45).

*I have always felt my most important calling is that of a parent or father. It has been the most rewarding things I have ever done in my life. Children are entrusted to us by God, to watch over, guide, support and love. Raising my three sons has brought meaning to my labor – a reason for being.*

*Ironic, the same role which brings meaning, is changed so much when your children become young adults – and question and reject (at least temporarily) your guidance and direction and thoughts and feelings, to find their own. I know it is the way of the world – we all in some respect do it – break the bonds and push back on those who loved us so. But I have seen how it all comes back full circle – with my own parents – that allows me to hold hope and wait for the bonds to return.*



*Figure 41.* Dustin's picture of how Graves' disease changed his life.



*Figure 42.* Dustin's picture of empathy.



*Figure 43.* Dustin's picture of a place where he feels safe.



*Figure 44.* Dustin's picture of a confidante in his life.



*Figure 45.* Dustin's picture of a role in which he feels most valued and appreciated and unsupported and invisible.

### **Missing Data**

All eight participants included a response to five questions: how Hashimoto's or Graves' disease has changed their life, what gives energy to them, a safe place, a confidante and their signature. It is important to mention the data that was missing in the participants' notebooks. Four out of the eight participants did not avail themselves to an in-person follow up meeting. Their completed packets were mailed to me or left in an envelope at their office. Participants did not include a photo for all of their written

reflections and photos were included that were not attached to a written reflection. Three of the participants did not include written reflections for the two questions at the end of the project. One participant did not include demographic information outside of gender, age and diagnosis in her initial email correspondence. Five participants did not respond to the question about empathy. Two participants left the following questions blank: family, a favorite meal, comfort clothes, public clothes, a role of invisibility, a role affected by the thyroid condition. One participant left the following questions blank: location of medication, anxiety, community, stress, love, role of value, what is healthy, future dream, passions, what brings a smile and what takes energy away.

### Discussion

In narrative analysis, there is recognition that the stories of our lives are co-constructed in community. The role of *outsider witness* is one of curiosity and genuine exploration. On some level, sharing and witnessing narrative is honoring the ancient archetype of healing. The shaman heals the sick person through directly accessing his or her inner knowing and the power of connection to the entire village.

As I held the stories and images, absorbing the experiences and reflections of the eight participants, I was overwhelmed by their powerful depth. Only one word captured the weightiness of what had been given to me as a researcher: sacred. The stories the participants entrusted to me are sacred. I was conflicted about how to present their stories. In qualitative research, the researcher becomes the teller. The researcher constructs meaning from the data. The researcher reduces, defines, analyzes and finds themes. As I began this process, I kept hitting an impassable wall. Their stories are their

stories. I cannot tell their stories. I can hold space for the sacredness. I can only reflect on how their stories stir my own story. I, as the researcher, am witness.

Within a narrative paradigm, the witness responds in four distinct ways (Freedman, 2012). First, the witness identifies the expression. As I listened to the stories of the lives of the participants, which expressions caught my attention or captured my imagination? Second, the witness describes the image. What images of the participants' lives, of their identities, and of the world more generally did the expressions evoke? What did these expressions suggest to me about their purposes, values, beliefs, hopes, dreams and commitments? Third, the witness embodies a response. What is it about my own life and work that accounts for why these expressions caught my attention? Do I have a sense of which the aspects of my own experiences resonated with the expressions and images? Fourth, the witness acknowledges transport. How have I been moved on account of being present to witness these expressions of life? Where has this experience taken me to that I would not otherwise have arrived at, if I had not been present as a witness to this narrative research? In what way have I become other than who I was on account of witnessing these expressions, and on account of responding to these stories in the way that I have?

In my witness of the eight stories, I remained open to how they reflected my research question. What is the lived experience of people living with thyroid autoimmune conditions and their relationship to self and others? I listened for snippets of lived experience of autoimmunity, story of self and connection to other. I was equally influenced by my curiosity around recognizing and being recognized.

### **Identifying the Expressions**

The first step in the witnessing process is identifying the words and reflections that caught my attention. As I listened to the stories of the lives of the participants, I took note of which expressions caught my attention. I have written up summaries for each participant, mirroring the format of the findings section.

**Witnessing Skye.** As I read Skye's poetic reflections and looked at the pictures she captured, I noticed her profound insight into who she is and what she likes. Her self-perception of not having courage to voice her knowledge did not fit with how I experienced her. I found it interesting that she signed her name twice because she did not like the first signature. I was drawn to the tension between a playful, curious child and an exquisite, radiant woman of Divinity. I was struck by her repeated mention of being invisible. I resonated with her expressions of seeing the real me, the True Self, and finding a home where all that is required is awareness and rest. The photo filled with images of children smiling, roller skating, dreaming and flying, held and supported by a mysterious, majestic woman sent chills through my body.

**Witnessing Christine.** As I read Christine's flowing, flowery writing and observed her pictures, I heard her longing to become a woman with a peace lily spine. I noticed Christine's desire to have loyalty without judgment in her connections with other people. I found it curious that her picture of health was given to her by another person, her father, who was an organic sheep farmer who could not taste or smell and drinks as a result of living through war. I paused and contemplated how a life that was stuck "ON" would create a feeling of never being fully put together. I was intrigued by the spectrum Christine created with writing, invisibility and forgotten on one end and educated

extroversion on the opposite end. I was honored by Christine's courage to put herself in the photos in the midst of her life-long insecurity about her weight.

**Witnessing Ash.** Ash's words emitted a playful, honest energy, as she expressed herself and then talked to herself in parentheses. I was struck by her need to hide and hold her extensive pill collection in a colorful basket that represents her. I resonated with the incomprehensiveness of sick and young being in the same sentence. I noticed the tension between what is selfish and what is self care; what is creative and what is copying someone else's idea; of deciding my own future or having it decided by someone who does not know me; of what name best fits me. Her image of being cocooned stuck with me. A safe place where I can rest, feel safe enough to be me, gently touched and supported by something firm so one day I can be who I wish to be. I appreciated how she talked about knowing she was important because of public expressions of love. I noticed the profound energy in her statement about trusting her husband because he is still here after all the stress and chaos.

**Witnessing Alice.** As I read Alice's short words, written in random capitalization, I was struck by the simplicity of her story. I, myself, was affected by this disease and I, myself, own the choice of how it will change me. I felt the most poignant of her words, and the accompanying picture of two trees on a window sill, deep within me.

*Forever is a long time – what would happen if I was stranded on a desert island?*

I noticed that her daughter was the person with whom she shared herself most honestly. I found it interesting that her definition of Love included not wanting to be seen and wanting to be somewhere else. Her picture of her bedroom and dog included a

sense of being safe and keeping others safe. I heard her hope that one day her dreams will grow to support her and will become visible for the world to see.

**Witnessing Maggie.** As I held Maggie's story and images in my awareness, I noticed her hope from seeing both sides of the coin. Knowing the limits of the energy reserves within herself, she recharges in the comfort and quietness of a red chair. The process of learning how to balance and regulate may be long, yet it is manageable. Her collage of words was beautiful. With everything connected in patterns, she was able to navigate her way through it gracefully. I noticed the sadness and grief of taking on a role one did not choose and the desire to have shared experience with the people who are important in our lives. I resonated with the comfort of being welcomed upon return by accepting, genuine people who have been part of my story for a very long time.

**Witnessing Jessie.** In the middle of Jessie's written reflections and images, two particular things struck me.

*The nuns hammering a fat pencil on the top of my head.*

*Lost him on the operating table and it ripped my heart to shreds.*

I was moved by the loss of not being able to express who she and the love she holds in her heart. I noticed how Grave's disease affected her ability to see details clearly and lessened the ease with which she excelled as an accountant. I found it curious that her confidence of managing money professionally transformed into anxiety in her personal life and finances. The theme continued when she talked about fine points sliding too quickly over the paper. She feels more secure with medium pens that are broader and slower. It is important to take time to slow down and age with vibrancy and wholeness. Her statement that one day her health might cost her more than she has to



spend was profound. I wondered why Jessie typed all her responses and chose to use photographs that were not her. Someone else, someone who I do not know, and may not be real, represents me better than I represent myself.

**Witnessing Annie.** As I held space for Annie's written reflections and images, I was surprised by the power contained in her limited responses. She left most of the questions blank. She included only a couple of photos. Most of her responses were in the "write in your own" sections. Of all the participants, her images aligned most closely with her written reflection. I could hear her voice come out of the photos. I was struck by the photo of her two selves lying next to each other: pre-Hashimoto's and post-Hashimoto's. I noticed how often Annie spoke of doctors not listening, not caring, not understanding, not interested, not validating her story and not giving her what she needs. I resonated with her the scary reality that her life is in bottles, filled with pills made in a faraway place. I was moved by her description of the door and the courage it took to walk through it. I was surprised that she thought her husband and best friend knew her better than she knows herself. I do not have words for the beautiful honesty reflected in her signature. I was struck by Annie's correlation between trust, safety, warmth, hiding and overwhelming outside intruders.

*Everyone needs a place to hide. I'm glad my place is so accessible to me.*

This was a deeply meaningful statement for her and me as a witness.

**Witnessing Dustin.** As I witnessed what Dustin shared, I felt a deep sense of thoughtfulness and intention within his words and images. I watched his transformation and personal growth. I was intrigued by his unique signature signed twice, once in pencil and once in pen. I was struck by a typo which created powerful symbolism. Instead of it

(strength) has returned, he wrote I has returned. Graves' took away much of me but I have come back. I noticed his philosophical insights into who he is, how much he chooses who he is and how much is dependent on the biochemical soup flowing inside his veins. Empathy comes from realizing the circumstances that keep people from becoming who they wish to be is not always something they can consciously control. I noticed how many times the word balance came up in his reflections. I found it curious that not afraid to be real and genuine and going somewhere all by himself and feeling safe were part of his definition of being comfortable. I sensed the irony and pain of discovering the reason for being is also filled with disconnection, broken bonds and patience as one waits for returned love.

### **Describing the Image**

After witnessing the words and images of the eight participants, one picture of my own emerged (see Figure 33). It was born out of three of the participant's stories, Dustin, Jessie and Skye.

*But I have seen how it all comes back full circle – that allows me to hold hope and wait for the bonds to return.*

*Sunshine. I am a sun person and love the sun, always have. I am the happiest in the sun. I get energy from the sun and my skin glows from it. It puts me in a great mood and provides the energy and stamina to get much done in my life.*

*What can I say but that the sun is my energy much like a solar powered engine.*

*Sunrise, sunset, sun, any kind of light gives me energy...pictures or paintings of sunlight coming into the scene or a light source in a room shining on a scene. In my home, I have many lamps in corners or behind furniture which emit a hidden*

*radiance. I love to walk in the evenings when people are just turning on their lights. Seeing the lights from within the home or their outside lights shining is very soothing to me. I even rate from one to 10 how the lights are affecting me.*

As I look at the picture of the four people, connected in a full, complete circle, I see the radiance of the light dancing in the middle. The light might be holding them together. The light may be what drew them together. Story is light. Stories are how humans become visible to each other. Story connects people to each other and strengthens bonds to one another. As humans stand together, we create safety to come out of hiding, to express our voice, to rest, to find our True Self, to grieve the loss of health, to welcome each other into the fullness of our humanity. Though the medicine of listening to and speaking story, I experience connection to myself and to others.



*Figure 46. Ivy's Image of Witness*

### **Embodying a Response**

I met something of myself and my story in each of the participants. What I noticed in their stories was deeply tied to pieces of my own story. During the process of collecting the data, a participant knew a dog named Ivy Wagner, I road-tripped to the

East coast home state of one of the participants and I met the aged embodiment of a best friend from childhood in another participant. My cancer was found at a routine yearly physical. I do not eat gluten. I wanted to be a graphologist as a child so I excitedly lived my dreams through looking at the participant's signatures.

I have remained hidden for most of my life, wearing masks that kept me safe and protected. I have longed to be understood and welcomed into a place that has known me since before I was born. I am caught in between a child and a woman. I can barely remember the self I was before I was diagnosed with thyroid cancer. I sit in chairs to recharge myself and my energy. I want to rest, yet I often find myself stuck on. I forget details and feel dizzy. I wish to be someone I am not and in the process neglect the person I am. Healthy is a choice that can collect dust in my life. Massage therapy grounds me. Collages describe my life better than lines. I like color. Nature gives me life. The ultimate test of loyalty is staying with me after seeing me stressed out and off my medication. I fear what might happen if I lose my pills. When I travel, it is the only thing on my packing list that I double and triple check. I hope one day my dreams will support me financially. I know the tension of the fear and freedom found in being seen, being heard and speaking my voice. I have been on a quest to discover and express the most genuine self inside of me and find a Home that will witness it well.

### **Acknowledging Transport**

I have been moved on account of being present to witness these expressions of life story. In the process of preliminary research for this paper, I discovered I had thyroid autoantibodies at the time of my surgery for cancer. For 14 years, I lived without this knowledge. I found it written in a doctor's note on a single sheet of paper in the stack of

papers in my medical file. Over time, my thyroglobulin antibodies disappeared. As a result of doing this research, I wonder how much of the change correlates to my coming into my own person and discovering a congruent life story. Gluten intolerance (suspected Celiac Disease) arrived during the most disconnected chapter of my life.

Being present as a witness to this narrative research has shown me that I am not alone in my illness. My unique story is connected in meaningful ways to hundreds of thousands of other stories. I have become other than who I was because I witnessed and responded to these stories. In the process of writing this paper, I came to realize I have been living off doses of miracle grow and I want to root myself in deep, nutrient rich soil. I acknowledged my fear of dying and how it has kept me from connection. I explored my anxiety-ridden pattern of leaving things unfinished. I learned how to ask for help. I became aware that I am always searching for something that is lost. I will feel unsettled and unfocused until I find what is lost: a sense of belonging, of Home. I named the deepest, most genuine expressions of me: advocate healer, vision explorer, teach inspiration, love creator, hope writer. I experienced deep integration of my life story. This research and the stories I witnessed were catalysts for the growth of Ivy. For this, I am deeply grateful.

### **Strengths and Limitations**

This arts-based, phenomenological, narrative research approach was outside the conventional methods for my Master's program. A qualitative research design enabled the exploration of a theory that has little empirical evidence in published literature. Narrative analysis allowed the participants to tell their story with their own voice. Unfortunately, this type of research does not honor the usual social scientific

considerations such as operationalization of variables, use of controls and rigorous casual analysis necessary to prove relationship or causation.

Recruitment throughout the University of Saint Thomas' daily news gave credibility to the study and reached a wide population of people. Men and women living with Graves' disease and Hashimoto's thyroiditis were represented in the study. Stories from different cultural and ethnic groups would have enriched the research.

The time required by participants to complete the project was greater than originally predicted. This may have played a role in the incompleteness of several of the notebooks. The process of initial meetings, waiting for data collection, arranging a second meeting and developing the film took longer than anticipated. As a result, I could not be with the data as long as I would have liked. I was overwhelmed with the quality and quantity of story, written and visual, that the participants shared with me. I was not able to include all the data in this research paper. Given the time constraints of deadlines, I was not able to process, synthesize and connect the data to past and present knowledge and future theory as deeply as I desired. My own story and perspectives significantly influenced the research process. Inviting a larger community of witness would have brought in new perspective that would have enriched the discussion of meaning, reliability and validity of the study.

As a dual degree researcher, I was invited into the challenge of holding Clinical Social Work and Holistic Health Studies together. The worldviews and research parameters often collided. I ventured into unknown and uncharted territory. After creating the template of questions for the PhotoVoice project and receiving the participant's stories, I attended a week-long Narrative Therapy workshop in Chicago.

The narrative worldview supported and disrupted my theoretical lenses. I created the project as a way to get snap shots of the participants' lives. I hoped to see the pieces of their identity, in a concrete, defined way. Narrative paradigm honors a storied identity that is changing and fluid. Despite this shift in perspective, the combination of photo and written reflection served its purpose brilliantly: it collected story.

### **Implications for Social Work and Holistic Health Practice**

Social work is a profession that promotes social change, problem-solving in human relationships and the empowerment and liberation of people to enhance well-being (International Federation of Social Workers, 2000). Clinicians' ability to hold safe space for story is vital to client well-being. It allows the voice and experience of clients to become visible. This research revealed the power of image and story as foundations of healing and justice. Incorporating creative arts and narrative practices into healing work enhances the possibility of heightened self-awareness and sense of connection.

Deconstructing problem saturated stories, viewing things from different perspectives and reauthoring a coherent narrative are keys parts of a narrative therapeutic approach. Through taking pictures, participants were able to externalize pieces of their life in order to look at them in new ways. It is important that people living with physical or mental illness are able to conceptualize themselves and their problem as separate and not the same thing. Instead of asking about how long someone has been sick, it is important to reframe the question by inquiring how long the illness has influenced someone and his or her life.

This research revealed the interconnections between mental and physical health. The findings and stories contribute to increased awareness of and sensitivity to the

myriad of ways autoimmunity affects the lives of clients – emotionally, vocationally, physically, financially, vocationally and spiritually. People must always be seen within a contextual environment. Understanding the synergy between psycho-social-emotional-spiritual aspects of well-being will enable innovative, creative and preventative clinical approaches to flourish. As a result of hearing sacred story, clinical social workers will become stronger advocates for holistic social change.

### **Critical Reflections and Future Research Considerations**

Through this research study, I hoped to create new understanding about the connections between identity, community and autoimmunity. The choice of PhotoVoice methods and narrative analysis confined implications to exploratory purposes and cannot alone validate theory.

The stories of the participants point to provisional possibility that Hashimoto's thyroiditis or Grave's disease could be connected to how one is recognized, seen and received by his or herself and others. Energetic and emotional realities may manifest themselves in the physical body. An incongruent story could be a risk factor in disease. Many participants spoke of invisible roles, the desire to be heard and seen and difficulty in manging the defintion between self and other. My findings support the only published reasearch studies tied to my concept of mental autoimmunity. Torem (2007) provided case examples of mind-body hypnotic imagery treatment of autoimmune disorders. With a woman living with Multiple Sclerosis, her confused and misguided immune system learned to tell the difference between cells and tissues that were part of her own body and those that were representing foreign pathogenic invaders. Through imagery, all the cells and tissues in the woman's body were tagged with the letters J.P. (her initials), which



meant they were safe from being attacked by her immune system and were part of the organism in which the immune system resides. It was crucial that the cells and tissues throughout her living organism recognized each other as part of the same living self and worked together in a friendly, harmonious way. Several months after the treatment, the woman reported continual remission, functioning well at home and work.

Future research considerations are many. Creation of a PhotoVoice template which narrows the focus and multiplies the questions eliciting responses supportive of the theory of invisibility and recognition would be beneficial. A qualitative interview where participants tell their story, using more traditional narrative approaches is needed. A study exploring Family System Constellations, creative arts and narrative therapy's influence on symptomatology of clients would be helpful. Looking at identity and community within a focus group would add interesting elements to the research. Administering Skowron's Differentiation of Self Inventory or a scale looking at dissociative symptoms with people with autoimmune conditions may reveal further connections between self and disease. Doing comparative study among people with various types of autoimmune diseases, from different cultural groups, in different regions of the United States, in rural and urban settings would create vital knowledge about this invisible disease affecting growing numbers of people. Further exploration to determine if a loss of identity and community were present before the autoimmune diagnosis or as a result of the diagnosis would be intriguing. Deeper understanding of how disease process is influenced by psychoneuroimmunology and the stress of not having a congruent story because of loss and trauma is needed. The efficacy of a consistent, constant dose of thyroid hormone replacement, in the midst of changing cycles of regulation due to stress,

would be beneficial to understanding the best methods of treatment of thyroid autoimmunity.

## **Conclusion**

The purpose of this research was to explore the connections between identity, community and thyroid autoimmunity, adding to the emerging and growing understanding of the current epidemic of autoimmunity. This arts-based, phenomenological research study captured the lived experience of eight participants who provided photographs using modified PhotoVoice methods and written reflections through open ended questions in project notebooks. Findings support further exploration of mental autoimmunity, the inability to emotionally and spiritually recognize and voice the story of self, and its role in a person's susceptibility to physical autoimmune conditions. When the permeable boundary between group and individual identity, personal and communal roles become confused or non-existent, humans may begin to question their identity and how they fit into the social community because they are not recognized and welcomed for who they are. Disconnection and autoimmune disease may emerge as energy flow and communication are disrupted. The story of self is connected to community and safe space must be created in clinical realms so people who are living with hidden illnesses can tell their sacred stories and be witnessed by listeners.

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## Appendix A

### CONSENT FORM UNIVERSITY OF ST. THOMAS GRSW 682 RESEARCH PROJECT

#### **Thyroid Autoimmunity: Lived Experiences of Identity and Community**

You are invited to participate in a research study exploring how thyroid autoimmunity affects our lives, our sense of self and our relationships to other people. You were selected as a possible participant because you are between the ages of 25 and 66 and you are living with a thyroid autoimmune condition. Before agreeing to be part of this research, it is important that you read the following explanation of the study and ask any questions you may have.

This study is being conducted by Ivy Wagner, a graduate student at the School of Social Work, St. Catherine University and University of St. Thomas, Saint Paul, Minnesota. I am supervised by Kari L. Fletcher, ABD, MSW, LICSW, University of St Thomas and St. Catherine University School of Social Work Assistant Professor.

#### **Background Information:**

The purpose of this study is to explore the lived experience of people living with thyroid autoimmune conditions. I was diagnosed with thyroid cancer and Hashimoto's thyroiditis when I was 16 years old. I desire to understand why the body does not recognize itself as self and begins



to destroy healthy tissues and cells. The information obtained through your stories will deepen our knowledge of how the mind and body interact with each other.

### **Procedures:**

If you agree to be in this study, I will ask you to do the following. I will give you a disposable camera and a notebook. You will complete a short demographic survey to give a context to the thyroid condition and will take 24-27 pictures of certain aspects of your life. You will be provided with a detailed list of instructions. For example, take a picture of a place where you feel safe. Take a picture of something that makes you smile. Take a picture of what healthy looks like for you. The photo opportunities were created to be simple and non-evasive. After you take each picture, you can jot down what the picture is of, why you took the picture and any thoughts, feelings or stories that are tied to the picture. You will have two weeks to complete the project. After you complete the project, you will contact me and I will meet you to collect the camera and notebook. We will have a short (5-10 minutes) conversation about how the experience was for you. The conversation will not be recorded. I may take notes. I will develop the photos onto a CD and will read what you wrote in the notebook. A modified version of PhotoVoice research methods will be used to examine the materials. Common themes will emerge to inform the research. I will share the findings from the data with my research committee, during a short public presentation and in a bound book which will be kept at the University of St. Thomas and St. Catherine University libraries.

### **Risks and Benefits of Being in the Study:**

The study has no risks.

You will receive a personal scrapbook that contains your photo and written contributions, as well as the study results.

### **Compensation:**

No monetary compensation is given.

### **Confidentiality:**

Your photos and notebook will be kept confidential. Research records will be kept in a locked file in my apartment. Information you provided in the initial online survey will be kept in a password protected file. My chair and four committee members may see the photos and notebook, but will not know who you are. Any identifying information will be deleted. If photos are chosen to be shown at the presentation or in my paper, all faces will be blurred. The data may be kept to inform future research.

### **Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. You may skip any photos or questions you do not wish to answer and may stop the project at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, if I have received your notebook and camera, the data collected about you will be kept confidential. It may be used in my research.

### **Contacts and Questions**

My name is Ivy Wagner. You may ask any questions you have now. If you have questions later, you may contact me at xxx-xxx-xxxx. My research chair, Kari L. Fletcher, can be reached at xxx-xxx-xxxx. You may also contact the University of St. Thomas Institutional Review Board at xxx-xxx-xxxx with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Consent:**

I have read the above information. I understand what is being asked of me. My questions have been answered to my satisfaction. I consent to participate in the study and agree to share my photographs and writing with the researcher. In accordance with law, I will **not** take pictures that contain nudity, are graphically physically revealing or are of children in private settings who are not my own children. I also understand and agree that unless otherwise notified in writing, Ivy Wagner is granted permission to use the photograph(s) in her paper and/or presentation.

\_\_\_\_\_  
**Signature of Study Participant**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Print Name of Study Participant**

\_\_\_\_\_  
**Signature of Researcher**

\_\_\_\_\_  
**Date**

**Appendix B**

## CLINICAL SOCIAL WORK AND HOLISTIC HEALTH STUDIES

### GRADUATE STUDENT SEEKS STORIES FROM RESEARCH PARTICIPANTS



- Are you between the ages of 25 and 66?
- Are you living with Hashimoto's thyroiditis or Grave's disease?
- Are you open to taking 25 pictures of your life and jotting down some thoughts in a notebook?

All genders and ethnicities are invited to participate.

Participants will receive a personal scrapbook that contains your photo/written contributions, as well as the study results.

Ivy is a graduate student at Saint Catherine University and the University of Saint Thomas. As a result of having thyroid cancer and Hashimoto's at age 16, she has dedicated her research paper to understanding how thyroid disease affects our lives, our sense of self and our relationships to other people.

**If you are interested in learning more, please email Ivy at:**

**[wagn1077@stthomas.edu](mailto:wagn1077@stthomas.edu)**

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# What does your life look like?



Read through this list two or three times. Become aware of what comes to mind for each item. You can take a picture of a picture. You might draw something or write out a word and take a picture of it. You could have someone take a picture of you. You can decide what order you'd like to take the pictures in. Please note the number on the film next to each picture description.

After you have taken the picture, please briefly journal. Jot down what the picture is of and any thoughts or feelings associated with the picture. You might want to reflect on why you took the picture. Did you take it because you thought it'd make someone else happy or you should do it a certain way? Or it is truly an expression of you? Feel free to include stories or poems. If you need more room, you can write on the back of the piece of paper.

This is an opportunity to show me who you are. There are no right or wrong ways to take the photos. There is no judgment about what you write. Please express yourself and your voice freely. This project is about sharing yourself and your experiences. Be as creative or simple as you wish. All photos and writings are voluntary. You can skip any photo or question.

Thank you for your time and energy. I look forward to hearing from you when you complete the project. You have up to two weeks. If I do not hear from you by \_\_\_\_\_, I will contact you. I appreciate your willingness to partner with me in this important project. If you have any questions or concerns, please email me at [wagn1077@stthomas.edu](mailto:wagn1077@stthomas.edu).

Grateful for your stories,

Ivy Wagner

Take a picture of something (an event, activity, location, experience, etc) that gives you energy?

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of something (an event, activity, location, experience, etc) that takes energy from you?

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of a place where you feel safe.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of someone who is a confidante in your life.

Picture number on film: \_\_\_\_\_

Reflections: How do you know this person is trustworthy? When has he or she seen your genuine self? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of what being healthy looks like for you.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of your favorite meal.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of yourself in your favorite comfort clothes.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of yourself in your meeting the public clothes.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of empathy.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of how you express your passions and giftedness.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Think about the roles you play in your life. It may be brother, mother, teacher, child, artist, employee, spiritual seeker, etc. Take a picture of the role in which you feel most valued and appreciated.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of a role in which you feel unsupported or invisible.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of the role most affected by your diagnosis of a thyroid condition.



Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of a future dream or goal.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of anxiety.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of something that makes you smile.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of something that reminds you of your family.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of stress.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of love.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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On the following page, there is a blank sheet of paper. Please sign your name on this piece of paper. Take a picture of your signature.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of how Hashimoto's thyroiditis or Graves' disease has changed your life.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of where you keep your medicine and/or supplements.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Take a picture of a community or group of people to which you belong.

Picture number on film: \_\_\_\_\_

Reflections: What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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There are four remaining photos on your camera. If you choose, you can take pictures of whatever you'd like to share about yourself, your life or your relationships. You might want to take additional photos of how Hashimoto's thyroiditis or Grave's disease has brought change and growth into your life. Or what rest looks like for you. You could take a picture of how you see yourself, how others see you and how you wish to be seen. You do not have to take additional photos.

Picture number on film: \_\_\_\_\_

Reflections: What is the caption or title of this photo? What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Picture number on film: \_\_\_\_\_

Reflections: What is the caption or title of this photo? What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Picture number on film: \_\_\_\_\_

Reflections: What is the caption or title of this photo? What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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Picture number on film: \_\_\_\_\_

Reflections: What is the caption or title of this photo? What is happening in this picture? As you took this picture, what feelings, thoughts or memories did you experience? What story is this picture telling?

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**After completing the project, please reflect on these two questions.**

What did you discover about yourself?

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What did you learn about how you interact in your world and relate with other people?

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Please fill out the following questions to the best of your knowledge. All information will be kept confidential. The questions will give context to the diagnosis of the thyroid condition.

1) Please circle your gender. Female Male Other \_\_\_\_\_

2) In what month and year were you born? (MM/YYYY) \_\_\_\_\_ / \_\_\_\_\_

3) Please circle which condition you have been diagnosed with.

Hashimoto's thyroiditis Graves' disease

4) In what month and year were you diagnosed with this thyroid condition?  
(MM/YYYY)

\_\_\_\_\_ / \_\_\_\_\_

5) When did you first notice the symptoms of the thyroid condition? Did any significant life events occur in the year the symptoms began?

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6) Have you been diagnosed with other health conditions or autoimmune conditions? Please explain. Autoimmune conditions include Rheumatoid arthritis, systemic lupus erythematosus, Type 1 Diabetes, Celiac disease, Crohn's disease, Ulcerative colitis, Inflammatory Bowel Disease, Addison's disease, Vitiligo, Multiple Sclerosis, etc.

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7) Have your family members (parents, grandparents, children, grandchildren, siblings, aunts, uncles, cousins, significant others) been diagnosed with any autoimmune conditions? Please explain who and what condition.

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8) What cities have you lived in from the time your mother was pregnant with you until today?

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